

**People Leading Accessible Networks of Support (PLANS)
Family Support 360
Statewide Workgroup
Chamber of Commerce
Pierre, SD
June 28-29, 2004**

CALL TO ORDER

Clint Waara called the meeting to order at 11:00 a.m., June 28, Monday.



Members Present were:

Cindy Taber
Ronda Williams
Ted Williams
Beth Hosek
Dawn Kellogg
Kristi Heumiller

Clint Waara
Michelle Powers
Linda Daughters
Travis Arneson
Mary Funge
Vikki Day

Tim Neyhart
Brenda Smith
Ann Rieck McFarland
Dan Spotted Eagle
Shirley Stirling

Others Present were:

Brooke Lusk
Donna Olivier
Patrice Wilson

Lisa Lunstra
Tarra Stoesser
Carol Ruen

Wanda Seiler
Arlene Poncelet

Path Plan Discussion – Brooke Lusk

Strengths, Ground Rules, Weaknesses, Goals, Etc.

Goals for the grant:

- Person-centered
- Establish relationships with stakeholders and make sure they share our vision. The group needs to think about how we are going to share the Plans Map.
- Identifying funding and training needs.
- State website documenting families stories.
- Capture everyone's ideas to your satisfaction? Who do you want to share this with? Stakeholder, families, or just for us?



Group input:

The group discussed steps/goals and vision.

Some areas of concern are:

- It could be a threat to some people who are not at table.
- Don't want to alienate people.
- Summary document should contain major steps and goals in an abstract format.
- Remove the word threatening.
- Goal – stakeholders support to what role people play.
- Evolving takes work and time.
- What groups are considered stakeholders? Families, 17 ATC's, Parent Connections, GRDSS, Advocacy, DOL, DOE, DSS, DOH and other similar agencies/organizations
- Will number the goals and identify the steps that are needed.
- Relate steps to goals and prioritize.
- Need timeline with steps.
- Education/Training - Do customers know what to ask? Should satisfaction surveys be implemented?
- How do we get this information out to families/individuals/teachers for future planning?
- Service coordinator learning about each community - need a contact person for each community.
- Sub-group to strategize how to address different stakeholders (could contain just a dialogue).
- Few workgroup members to meet with Wanda w/ SDACBS and other stakeholders in August (**need volunteers**).
- Will then be able to take public forums information to stakeholders.
- Assign sub-groups to specific objectives and group objectives in specific categories so that workgroup members can choose a standing sub-group would interest them.

**To Do – Grant Workplan**

- Discussion over sub-committees: It was suggested to have a Public Relations, Finance and Political subcommittees.
- It was voted on to wait until after PLANS Family Support 360 grant is submitted to assign committees.

Question: What mechanism will we use to review this document?

Answer: We will revisit in future meetings and revise as necessary.

Wanda will be giving a Plans update on July 16 to the Family Support council.

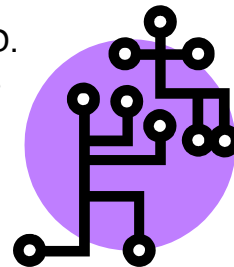


Guardianship Training & Interviews Update- Lisa Lunstra

- There is a need for a host family in each area where forums will be held, along with volunteers from workgroup to come and assist with one-on-one interviews.
- The forums will take place the first week of August.
- Fliers, along with interview questions, will be sent out to a variety of people. It was decided they will be sent out to hospitals, clinics, ATC, newsletters, local papers and families.
- Information will be given to Transition Liaison Coordinators. Mailing will go out from the Department of Human Services to the people that are currently supported.
- The workgroup can provide the additional contacts – families, stakeholders, etc.
- Confidentiality needs to be stressed, and host families will assist with contacting people in their area. The invite will extend the opportunities to adults and young adults.

Family Support – Deb Petersen, Division of Developmental Disabilities and three parents with children receiving services. Refer to handouts in binder.

- Deb is a Resource Coordinator with DD for central SD.
- The role of a Resource Coordinator is to help families complete application, determine eligibility, needs, and develop family support plan with the family.
- Currently 74 people have received services through the grant.
- They receive numerous referrals, which have been referred to the proper agency/organization that relates to their needs.
- They receive referrals from DSS, DOH, word of mouth, ATC's and other sources.
- This grant requires a state match.
- The program brochure, eligibility guidelines, etc. were distributed at the first workgroup meeting.



Family Input - Roger and Loretta (mother) from McLaughlin

- Roger has a provider who goes with him and takes him swimming at the school's pool
- If the program wasn't there they would probably go back to nothing – probably wouldn't have access to the pool
- The hardest part for them is the social interaction – partly due to the rural area they live in.
- After school ends, the social interaction becomes much more difficult.
- Doesn't see Roger attending ATC, or sheltered workshop. He is used to doing his own thing and setting his own schedule.
- They did ask Roger after high school what he would like to do and he said he wanted to stay at home.

Question: How do you perceive an ATC?

Answer: I see it as people have to follow the rules and it is probably a more structured environment than he is used to living in. Maybe this is wrong.

Question: If an ATC has only staff and not a building, would that be that appealing?

Answer: Yes, Roger and I are Native American and it is very important that we stay in our community. Would like the opportunity to receive services and still stay at home.

Brandon and Julie Schatt (mother) from Gregory

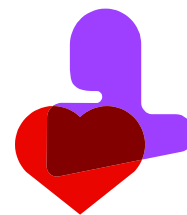


- Growing up, her only experience with Down's Syndrome was a female cousin who sat in the corner and rocked herself. They wanted more for their son and always will. He continues to surprise them and surpass their expectations.
- Brandon just turned 21 and his high school years are over – now what does he want to do?
- Went to ATC 25 miles away and had great work experiences but he wanted to move back home.
- He is currently studying for his driver's license exam; for a year and a half he has been living in his own apartment (6 blocks from home); maintains his own checking account
- Last year they got Brandon a cell phone because he's always on the go.
- He has a personal assistant who comes over about 6 hours a week. She helps with some cooking, shopping, laundry, maintaining checkbook and bills, organizes his schedule – he has two jobs right now, one of which is through Project Skills (Vocational Rehabilitation).

- She helps him organize his schedule by going through his calendar and this helps him keep track of birthdays, work, and budgeting each month.
- Part of what she does is socializing with him. Takes him out for ice cream, bike riding, playing pool, going to different sporting events. He is able to do some of this on his own because he does live in a small community.
- The community “watches out” for Brandon and she thinks living at an ATC would be a step backward for Brandon.
- He is on a bowling league, goes to church alone and meets his family there, is in a car club that was just established, made a male friend (co-worker) at the grocery store that he goes fishing with.
- Has a girlfriend in Gregory and they enjoy attending dances. “Everyone looks forward to watching them dance”.
- He is responsible and knows what he has to do and where he has to be.
- Julie doesn’t know what she would do without this program. They are very appreciative. He wants to stay in Gregory because of all the interaction with family and friends. For them, this program is a win-win situation.
- His parents are very proud of him and the choices he has made. They hope he continues to have choices in his life. They don’t want to see him have to fit into a program that may not be appropriate for him.
- She heard the group discussing the continuation of this program, it would be a lot less stressful if they knew that they don’t have to face a funding loss in the future.
- When you are making decisions within the group, imagine if it were you in this position, or your child.
- Brandon shared his view on how beneficial the program has been for their family. He has had great experiences and opportunities that otherwise he may not have gotten.

Clint Harris (father)

- Samantha Harris was born in 1986. She has Prader-Willy Syndrome. She was on a ventilator for first nine months of life. Reads and writes at kindergarten level. Understands thing at a teenage level. Her parents found out about her diagnosis in Jan 1987.
- What they really appreciate with the family support program is being able to discover the resources and services that are out there. It has been a great blessing to work with the program.
- This grant that the workgroup is working on is a big challenge but it is a wonderful thing for the people who need it. He encouraged workgroup to keep at it.



- Started family support program on a dream and a need. Clint would like services to run from birth thru adulthood seamlessly – no difference between child and adult.
- One of Samantha's treasures, framed article about her from the Capitol Journal. A reporter called the family and wanted to do a story about Samantha's accomplishments. They were reluctant to bare their family's story to the public but ended up very happy that they did.



Report from National Core Indicators (NCI) Subgroups - Tim Neyhart

- Essentially the summary of four sub-groups who looked at the statistics and came to several conclusions.
- SD ranked below average in choice and control over their services
- Some of the recommendations that the group came up with are: Supply enough information and training to service receivers, provide education, exposure and experience to individuals, give people the chance to participate in the hiring of staff and provide the means for services through a single point of entry system.
- Child family survey and the service coordinator– people are the happiest about this.
- Staff training is imperative – one person is expected to do three or four jobs for the wage of one job.
- Whatever it takes for you to get the same choices/opportunities that everyone else has.
- Large number of people said they didn't feel part of a community. Community is about inclusion and we need to address that.
- Loneliness was a big weakness in SD.
- Two things that showed up primarily: People feel they don't have choice and control over services, but they don't necessarily want them either.
- Again, families have said, "we don't know what we don't know."
- Many individuals are uncomfortable asking for info but they don't know how to ask for control.
- One of our key goals is and should be flexibility.
- Wanda stated that we are planning 2005-06 as the next cycle to participate in the NCI survey. South Dakota is part of the planning workgroup for the National Core Indicator survey so any feedback from the workgroup dealing with concerns, etc is appreciated.

Comments from workgroup

- Hope to see improvements in the next survey.



- Seems to be some inconsistency in stats i.e. SD rated low in choosing who you live with, but yet rated high on satisfaction questions.
- If people don't know what is out there, they tend to be content with what they have and know
- Interviewers who are asking the core questions cannot expand on the questions. For example, one of the questions is "Are you happy?" this can only be repeated as such and cannot be expounded upon. This seems to be too vague.
- Most of the people surveyed are around age 50.
- Survey needs to be done every three to five years.
- Native Americans only make up 7% of the people surveyed.
- Only the consumer survey was done on a one on one basis – the rest were distributed via mail.
- This is a good topic for providers, what are you going to do with this information? Agency specific results have been distributed to the service providers.

Question: Is the subgroup going to continue to meet?

Answer: We haven't discussed this. It will depend on the report and what we decide to do with it.

Question: Are there any guidelines that have come out yet as on how to interpret and improve the stats from the NCI report?

Answer: No, not specifically. There is a hope to do something for the agencies in the future.

Sales Tax & Food Refund Program and Food Stamp Program

Judy Tulley , Administrator

- The new program, Sales Tax and Food Refund Program started on July 1, 2004.
- The Eligibility criteria is income at or below 150% of the federal poverty level.
- Group home individuals are also eligible if they reside in a place where they receive less than 50% of their meals.
- The 50% or less meal provision must be a part of normal services provided to the residents.
- Application is one page consisting of four questions.
- Social Service offices have applications, no verification of income needed.
- Benefits can be used for the same items that food stamps are used for and the definition of food is the same as the food stamps program.
- Sales tax refund benefit will be sent every three months.
- Large number of people will be eligible for this program that aren't eligible for food stamps.
- Quarterly payments begin after you fill out the application.



Food stamps

- Participation for elderly and people with disabilities isn't as high as it should be because they sometimes only get \$10/month
- Pilot project has been approved on automated application for individuals who are already receiving SSI. The application will be used by SSI and the food stamp program.
- The standard allotment would be higher than the \$10 amount

Florida Development Disabilities Program - Susan Kaempfer, Bureau Chief of Community Program Initiatives, and Jennifer, parent from Ft. Lauderdale

Personal Care Attendant (PCA)

Consumer directed care (CDC)

Cash and Counseling

- In 1998 they started in Medicaid and then moved to Development Disabilities.
- Several populations of approximately 3000 people participate, including: elders, adults with physical disabilities and people with developmental disabilities.
- The DD group is about $\frac{3}{4}$ of the participants. They are very interested in directing their own care.
- The 1115 waiver allows parents/caregivers to be paid caregivers.
- The consumers hire their own workers.



Consultant services

- The support coordinator is eligible to become a consultant. Their role is to work with self-advocate and family to talk about consumer direction, budget, and purchasing plan.
- The consultant goes through training before they can work with families. The training is provided through the DD program.
- They work with the family most intensely the first year and then are not as involved unless needed.
- After 6 months, the family should be on "maintenance".

Budget Development

- Based on support plan that they were receiving through thru 1915c.
- Subtract the amount for consultant services and discount to 92% of full amount.
- An analysis of support plans revealed about 92% of plan actually received.
- The fiscal intermediary is actually in Utah and began in January 2004.
- They were given a monthly budget and the Department of Elder Affairs files the claims to Medicaid. The check is sent to the fiscal intermediary. As checks and invoices come in, then the fiscal intermediary writes checks for the self-advocate and then the self-advocate gives the paycheck to the employee.

Back up plans

- Everybody on a purchasing plan has back up plan for critical services.
- It is crucial to have a back-up plan and a back up worker for critical services, such as health or safety issues in the event the PCA doesn't show up for work.

Quality Assurance (Will send protocol to Brooke.)

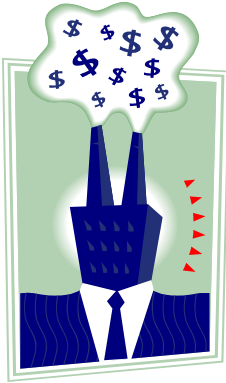
- Quality Assurance plan is in operational protocol

Jennifer – a family's prospective

- Used to be a support coordinator and a consultant. Left the field about three years ago. Her experiences seemed to be easier due to her work history.
- They had a governor who believed strongly in this program and director that totally supports this program.
- Consumer Driven Care (CDC) - Gives the consumer and self advocate a great deal of freedom but is not for everyone.
- Freedom from bureaucracy makes things easier for family and consumer to manage.
- She has a daughter named Ashley. Ashley is 20 years old and is still in high school.
- Ashley and I have in effect formed a partnership. We were determined to use the money the best way possible, by doing what is commonly referred to as "getting the most bang for our buck".
- Before CDC the agencies would charge them \$24/hour. They disliked paying \$24/hour for a service that didn't do much. Ashley is mostly self-sufficient and requires only minimal guidance in certain areas.
- Now they can hire people that are her neighbors, friends, families.
- Jennifer believes you need one more PCA than you plan to use.
- Ashley currently has 3 PCA's on the payroll.
- Ashley always has one peer PCA to attend high school functions with her. They are paid \$9/hour.
- They have a monthly budget – based on her needs prior to receiving support from CDC. Because they are cost-effective, were able to save a little money to purchase orthopedic shoes.
- In an emergency situation, if son/daughter lives at home and parent has no one to call, they can stay home and get paid for the lost wages. Sometimes you get the best care from those closest to you.
- Surpasses the lifestyle that you had before utilizing the program.
- By the 2nd year it is really not labor intensive. Most of the work the consultant does is in the beginning.
- Ashley conducts the initial interview with applicants, and if they pass her scrutiny then they get to go to Jennifer.
- Ashley can do the payroll and she is the boss. She lets the applicants know that right from the start.



- So grateful that we have this program. Every event we've had to turn to them, they have come through.
- This program won't work if the fiscal intermediary isn't performing the way they are supposed to perform, for instance you can't have a late payroll. The PCA won't work if they don't get paid and it is obviously important that payroll runs in a smooth manner.



- "Even with the bumps in road, it works."
- Helps you maximize your dollar and be more creative.

Question: Having to deal with fiscal intermediary – why do you have to go out of the state to get one?

Answer: Everyone asks that. We went to Virginia for the last one. Put out a Request For Proposals. Don't have to choose an out of state provider, that is just what they did and they do have a representative in Florida. Provides tech assistance, training. Fiscal intermediary is crucial to the success of this consumer-driven project.

Question: You mentioned that you have a two hour training for the attendants. Would it be possible for us to get ahold of that.

Answer: Yes, it would be. Doing a workshop for a training in September. Some information is specific to Ashley, so she is doing a more generic version. She will have handouts ready July 15. She will be happy to share as soon as it is ready to go.

Question: Have you ever considered having a self advocate becoming a consultant

Answer: Yes, that is one of the things we are doing with a program called the FL Freedom Initiative. (CMS grant that FL receives) Big piece of this grant is to train self advocate to be a consultant. There has been quite a few family members who have gone ahead and done it.

Question: Have you ever considered the possibility of having the fiscal intermediary having a lesser role?

Answer: We are open to that. One of the things that they have vowed from the beginning is accountability. One of the reasons we were so reliant on FI in the beginning is we wanted to make sure we had the accountability for the dollars.

Jennifer's answer: For the consumer – unless the fiscal intermediary makes a mistake, they don't play that big of a role. They don't play a big part in their life. Twice a month Ashley sends them a fax. That is the interaction she has with them. Don't have a large impact, unless they mess up. They don't usually make mistakes, it isn't a habit. They really do pretty much what the consumer tells them to do.

Question: I know that everybody's ability is different, my concept would have a monthly amount deposited into an account, if they have that ability. And when it came to paying someone, I know that taxes and what not are complicated, they could call in the hours worked, and the fiscal intermediary could tell the



individual the dollar amount. Then the individual could write out their own checks and the intermediary could help out with taxes and whatever you have.

Answer: Sounds kind of like a hybrid idea of what we had before. Before fiscal intermediary, we were our own bookkeeper.

Question: Are the PCA's considered self-employed?

Answer: No, you are their employer and they are considered to be an hourly employee. You could become your own agency, but it is a faster track to do it through the program.

Susan knows a National expert on fiscal intermediary if we have more questions. Her name is Sue Flanigan. Susan will send her phone number to Brooke.

Question: A question on the 1115 waiver. This waiver is on top of your HCBS waiver?

Answer: Yes, this is the Medicaid state funding that the state kicks in.

Question: If you did a 1115 waiver for people not on the HCBS waiver where would they get the money?

Answer: That depends on what the legislation states. If we had a separate appropriation for this, I don't know that we would have done a lot more differently. Maybe we could have served more people. I don't know that we would have set it up differently thought. Control group has a different way of looking a budget neutrality

Question: What were your differences in the total cost between the control and the experimental group?

Answer: Haven't seen any numbers from Medicaid this year. The last numbers she saw for the DD population, they were spending \$400 more than the control group. Went to standardized rates this past year in their DD system. Gave an increase for personal care service. She thinks they are doing better than they were.

Question: So are you using the new standardized rate system for CDC?

Answer: Susan: No, this is totally separate.

Jennifer: If I had \$100 I could spend on a PCA, I would hire 10 pca's for \$10/hour. The consumer may elect not to do all the direction of their budge, they can have a representative. The representative will work with the self advocate. For instance a mom could do it. Consumer can negotiate with representative what they want the rep to do. An example is that Ashley's math classes are based on how to do payroll.

Question: When Jennifer started talking about all the different ways they save money, has the state every calculated the total cost in terms of CDC against the person in the more traditional system?

Answer: Yes, that is included in a report. They look at state plan expenditures. There is an evaluation process taking place at this time. Some of the state plan services, such as physician, appointments are perhaps these expenditures when people are using their budgets in a more creative manner.

Jennifer: Besides the dollar amount, you need to look at quality of life. What is the quality of life. That should be the part that is driving decisions. Should look at the barriers for the consumer self advocate. A good consumer will max out their budget. They will utilize every dollar they can, but you still need to look at the quality of life.



SD Parent Connection – Conference Call with Dina Castro, Parent to Parent Coordinator, Family to Family Coordinator and Voice Coordinator

FOA – Family Opportunity Act

- Have 5 programs they run through the office. They include:
 1. TCI - state parent training and information center. We are the state parent training and information center. We do about 250 workshops around state each year. We send out quarterly newsletter. Have a resource center with books and videos that parents and professionals can check out. Get about 3000 phone calls per year.
 2. Family to Family – received family and healthcare grant and this helps supplement the program. Currently through the Centers for Medicare and Medicaid services. Grant runs 3 years.
 3. Parent to Parent program – linking program. Links parents to each other. Rural areas – parents feel isolated, this helps. A minimum of two contacts with another parent
 4. Family Voices of SD – national network. Good collaboration. Hope to run Family to Family Centers. Deal more with the healthcare side of things. Good source of education!
 5. Bright Lights – piloting in SF right now. Good for parents – right out of the hospital. Peer program. McKennan and Sioux Valley implement. The hospitals keep calling Julie back.
- In the Family to Family program, they are developing new workshops. Range from IEP laws to the grieving process that parents undergo when they realize that they have a child with a disability.
- IDEA most requested workshop. These are on their website: www.sdparents.org
- Three new workshops are in the development stages.
- She will send Brooke a brochure about the FOA.
- They are there to help parents find resources.
- They feel least capable about answering questions/problems dealing with transition.
- The best program they find is Birth-to-Three. Primarily because there is a single point of contact for the families.

Question: When/where/how trainings held?

Answer: They are held on request. They do teacher inservices, support groups, they go to hospitals. Mainly on request.

Question: We are looking at training needs for the grant. Would you be willing to implement new trainings based on the needs?

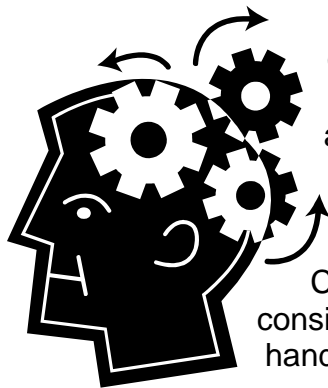
Answer: We could modify the trainings to suit the group's needs or look into new trainings. For example, we have a new autism and a new bullying workshop.

Question: Does Parent Connection focus on a specific age group?

Answer: We focus on birth to 21.

Question: I was just wondering if the Birth-to-Three program seems better because it's the first one that families experience?

Answer: No, I think it is because you have a central contact person – they are assigned a caseworker for this period.



Grant Input

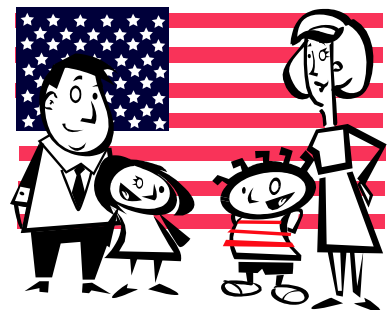
Brooke summarized what we need for input for the grant and what the guidance states. **Think broadly and with an open mind!**

To be thinking about: In relation to the Cash and Counseling model, the workgroup is going to have to consider workman's comp issues and how these will be handled, etc.

FAMILY SUPPORT 360 RFP

- \$250,000 for 3 years (**now changed to 5.**)
- faith based organizations
- Information and referral
- In-depth planning for at least 50 families
- 3 services each year
- criteria to establish if a family has achieved outcomes in their plan
- plan of action for self-sufficiency
- Models
 - Pros
 - Cons
 - Implementation

The workgroup broke into three small groups and then each group reported back to the entire workgroup. The responses were compiled as follows:



Ideas

Faith-based

- Jenny Thornburg, promotes inclusion in faith-based organizations.
- Continue to make connections with the ministerial organizations.
- Bring in presenter to discuss ideas with the families and other partners.

- Knights of Columbus organizations.
- Home visits from ministerial organizations.
- Transportation and participation (truly).
- Offering them the F/I job. Youth programs.
- Change pity attitude (charitable).

I&R

- Laundry list and places to advertise
- Coordinator – most important information – don't over share information – in system through one person and don't have to give lots of people same information over and over

Planning

- Has to be a person!
- Expertise to extend flexibility so person can choose to control
- more than yearly plan
- family/person centered

Services

- Personal Care
- Transportation
- Independent Living
- Day services, (job placement, social, recreation, companion care)
- Housing
- Education and training for everyone!!
- Medical needs (nutritional supplements, specialized medical equipment)
- Respite care
- Mental Health services

Criteria

- 18 and older
- Assessment from Council
- Using current family support plan and criteria
- Rehab model for satisfaction

Self-sufficiency

- all services should become Medicaid waiver eligible

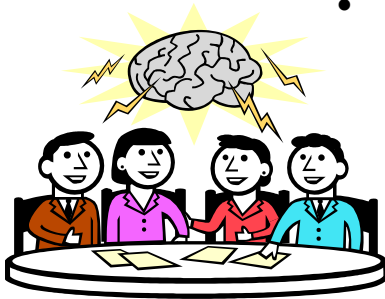
Models:

- Co-op model – seemed to be overwhelming task for families.
- Hybrid of FS and C&C (cash and council) -
- C&C more flexibility but it is also concerning. Liked idea of person.
- Family support model core – single point of contact – could grow into coop or C&C model
- Ruled out cooperative
- Everyone liked family support model
- Did like C&C but needed to build some supports

Tom Scheinost – SD Association of Community Based Services

College of Direct Support-online internet based training program
(Refer to Handout in binder)

- There is a relationship between Council on Quality and Leadership and the College of Direct Support.
- The initial task was a survey of direct professionals from across the state which showed a lack of available ongoing quality training.
- Individual staff is trained at their own pace. It is a learner tool that can be tailored to the agencies. This helps to better impact the agency's training.
- The course work can be made to reflect uniqueness of each group/program and are agency-specific. The courses are nationally validated. SD was the first state in the nation to fully implement the College of Direct Support. We have 18 of 19 ATC's and the Developmental Center participating.
- At the College of Direct Support most lessons take about 1 hour to 1 ½ hours. This can move toward an apprentice program with DOL.
- The goal of the project is to use the CDS to provide quality and ongoing training, and to enhance the morale of direct support professionals with the help of Department Of Labor.
- Future of the CDS - Looking at putting online for families to access



Possible date for next meeting in conjunction with Mike Walling training: AUGUST 24 AND 25TH. Based on Mike's schedule, a meeting date will be selected and you will be contacted with that information.